

Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders  
Legal Subgroup

1/7/2013, 9-10:20 am

Item Building

167 Point St., Providence, RI

---

Present: Jacqueline Lemoine (DHS), Anne Mulready (RI Disability Law Center), Parish Lentz (Davis & Lentz LLC), Joseph Proietta (Attorney at Law), Glenn Friedemann (Lifespan, Associate General Counsel), Stacy Paterno (Lifespan), Kathy Heren (Alliance for Better Long Term Care), Mark Sjoberg (Sjoberg & Votta), Tom Enright (chair, Partridge Snow & Hahn LLP), Lindsay McAllister (Office of the Lieutenant Governor).

1. The meeting began with group introductions. There were two new participants, including Jacqueline Lemoine from DHS and Anne Mulready from the RI Disability Law Center.
2. Tom Enright (Chair) asked both of them to share any legal issues in particular that they have encountered and would be pertinent to the work of the subgroup and State Plan.
3. Jacqueline mentioned that she sees some guardianship issues, for example, a client who had been in a hospital for over a year yet could not be discharged because he or she did not have a guardian.
4. Ann Mulready said that she felt the state's guardianship laws are fairly progressive in terms of thinking about less restrictive alternatives. The work her organization is involved in tries to think about maintaining capacity as long as possible and maintaining the client's ability to participate in decisions to the greatest extent they're able to. They use a BHDDH medical decision-making tool [info on this needed]. End of life decisions – with regards to who will make them and how - have been a challenge for them as well.
5. Lindsay McAllister provided an update from the Listening Sessions that have been conducted across the state to engage caregivers and others impacted by the disease who were unable to join the more formal working group/subgroup process. The input received so far has been fantastic. While the topic areas have generally tracked the subject matter being addressed by the subgroups, the Listening Sessions have provided a lot more detail, nuance and personal perspective that will greatly inform the Plan. An additional Session is planned for later this winter geared towards Spanish speaking families.
6. Tom Enright asked the group to provide feedback on some of the potential recommendations that had come out of our earlier conversations about guardianship. Judge Martinelli, who had been scheduled to address this meeting, was unable to attend because of a family emergency. Tom encouraged the group to think about what we recommend so far with respect to the creation of an Office of the Public Guardian, what other items are on our legal "wish list", how we could effectuate such changes, whether we recommend the Probate Commission commencing once again, and how these reforms might impact or be impacted upon by our existing statutory and regulatory structures.

7. **Parish Lentz suggested that we really need additional preventive measures in place: education and awareness of advance directives so that a person's initial interaction with assistive legal tools is not when they're already in crisis mode.**
  - a. For example there's a "40/70" formula be touted elsewhere. It is a campaign focused on age; once a child is 40 and their parent is 70, a conversation needs to happen- "does everyone have what they need" if the elder is incapacitated?
  - b. We should also work with RWU Law – there is an Elder Law student group and we should incorporate their perspectives on how they would communicate about these issues – how they'd use social networking to do so.
2. Glenn Friedmann shared that the American Health Lawyers Association has a DVD on these types of discussions. Its free. This could be a starting point.
3. Mark Sjoberg suggested that the group needed to parse legal decisions from medical decisions. A statutory power of attorney does not require a lawyer. In fact, primary care physicians need to encourage patients to have a power of attorney in their file with the doctor. It's a 4-page document and you fill in the blanks.
  - a. **We may want to think about trying to get the statewide form to include agent power to release health information. Some forms include this, but RI's statutory form does not.** HIPAA can therefore present some challenges.
  - b. Additionally, the medical community wants the forms updated periodically. Particularly in nursing homes – they'll ask for the code status to be updated. The individual will make a decision and the code status will change. The idea that a form is time limited is not ideal.
4. Kathy Heren explained that advance directives are formulated and then with every care plan update they're supposed to be revisited by the nurse and patient together. Its up to the nurses to review with the patient or family but oftentimes, this is not done.
  - a. Kathy added that discomfort by the family member or provider about what the patient is able to do and unable to do causes too much reliance on the Decision Making Assessment Tool (DMAT) and the Brief Interview for Mental Status (BIMS). These tools are used too often and too readily. Conversation about who the patient would want to help them if they were very sick can still occur despite some dementia, and should be a part of any process.
  - b. Kathy felt it is the medical directors at nursing homes and the primary care doctors who need targeting to increase awareness and use of advance directives forms. Fortunately, the MOLST will follow you everywhere once the regulations have been promulgated.
5. Mark Sjoberg added that this is a medical and ethical issue – attorneys ask their clients because they're doing estate planning and it becomes part of the list of questions, but its inappropriate to then get into a legal discussion about

extraordinary care measures. Hypotheticals are ok, but that should be the extent of it.

6. Glenn Friedmann said that Mass General uses a very detailed form that incorporates questions about extraordinary measures of care. **RI's Extraordinary Measures are too vague – more details would help docs and families to navigate this issue more effectively.**

- a. RI Bar Association has an end of life booklet 6-10 pages long. This has been helpful in the past and seems to be the only useful and widely available resource out there.
- b. **Our statutory form needs to be updated. The group agreed that building in an immunity clause – a statement negating legal liability for any doctor, or other community member for that matter, dispensing the form and encouraging its use – would be very helpful in fostering a higher comfort level with this document.**
- c. Glenn Friedmann recommended another form used in other states called the “Values Profile” – this gives advance directives through hypotheticals.
- d. **Another challenge for this subgroup is to think about how we improve public awareness.** We cannot rely on attorneys (not everyone uses an attorney regularly and we want to encourage using advance directives prior to “crisis point”), we cannot rely on hospitals alone (this wouldn't capture sufficient number).
  - i. What structures exist now that would work? **We should target primary care doctors offices.** More people go there than anywhere else – and on a regular basis. We need to target the primary care level. But this is twofold; if we're asking them to prompt the use of the document, **we have to improve the documents effectiveness and make it more available and accessible** (no “legalese,” simplify).
  - ii. **The form should be available on practice's online portals and on the contemplated “one-stop-shop” online resource for Alzheimer's and dementia.**
  - iii. **The group agreed that this campaign should include the development of CME courses for physicians.** Lindsay shared that all of the subgroups have been discussing the need for dementia-related CME credits and this would fit neatly into that recommendation.
  - iv. The group was unsure if advance directive forms became part of a person's health record and if the state's HIE project had contemplated including AD docs at some phase in the future. Lindsay will report back to the group on this.
  - v. **Another option would be to use the RMV as a touch point.** The group can revisit this option during its February meeting with the RMV representative.
  - vi. **Senior Centers were also mentioned as an potential touch point.** Kathy Heren suggested that a lot of other educational programs are conducted here and this would be a natural fit.

Lindsay agreed this would be a good idea and will report back on anything currently being done in senior centers on legal tools.

1. Joe Proietta added that at some point, the Bar Association had conducted an “Ask a Lawyer Program,” which was dedicated to healthcare powers of attorney (association for justice/trial lawyers association – RITLA may have also done something similar).
- e. Lindsay asked the group to consider what a good assignment for the RWU Law Students might be.
  - i. There are a few different organizations of students, including a Wills & Trusts group (80 students completing as a prerequisite to an elder law concentration), Elder Law Planning and a lab/clinic style group (20 students each).
  - ii. Parish Lentz suggested that we might use their perspective on Facebook/social networking as an opportunity to improve communication about these tools as well as their ideas on design/access for outreach.
  - iii. Kathy Heren suggested we should survey them on what they’re being taught about advance directives in their legal curriculum.
- f. Mark Sjoberg added that the Bar Association’s Probate and Trust Committee’s Subcommittee on Elder Law is looking at a number of items, though they’re now in legislative mode as we near the deadline for proposals.
7. Tom Enright suggested that a priority for the Subgroup would be to establish goals or “asks” of the Probate Commission. This would be an appropriate level of detail for the subgroup.
8. The next meeting will be on January 16<sup>th</sup> at 9 am – the location will likely be the same. We will be joined by two representatives from the Attorney General’s Office to discuss prosecution of elder abuse crimes. The February meeting will be focused on driving issues and revocation authority under the RMV.